NAVIGATING THE FOG

Living with Lewy Body Dementia

FREE PREVIEW EDITION

Malcolm David Crawshay

A practical guide grounded in lived experience

This is a **FREE Preview Edition** of Navigating the Fog: Living with Lewy Body Dementia.

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Medical Disclaimer

This book is not a substitute for professional medical advice, diagnosis, or treatment.

The author is not a medical professional. The content of this book is based on lived experience, personal observation, and reference to established medical and scientific sources. While care has been taken to ensure accuracy, medical knowledge evolves, and individual circumstances vary.

Always seek the advice of a qualified healthcare professional regarding any medical condition, treatment, medication, or change in care. Never disregard professional medical advice or delay seeking it because of something you have read in this book.

Safety & Responsibility Notice

Lewy Body Dementia can involve serious medical risks, including medication sensitivity, autonomic instability, delirium, and adverse reactions to anaesthesia and sedation.

The practical guidance and care protocols in this book are intended to support awareness, communication, and safety — not to replace clinical judgment. Decisions about care should always be made in consultation with appropriate healthcare professionals.

Personal Perspective

This book reflects the personal experiences and perspectives of the author. It does not claim to represent all individuals living with Lewy Body Dementia or all caregiving situations. What is described here may not apply to everyone.

No Liability

To the fullest extent permitted by law, the author disclaims any liability for any loss, injury, or damage incurred as a result of the use or misuse of the information contained in this book.

Acknowledgement of Variability

Lewy Body Dementia is a complex and highly variable condition. Symptoms, progression, and responses to treatment can differ widely between individuals. Readers are encouraged to use this book as a companion and reference — adapting what is helpful, and discarding what is not.

Note on Explanatory Models

Some explanations in this book use simplified physiological models or metaphors to help describe lived experience. These descriptions are not presented as definitive neurological mechanisms, but as practical ways to communicate what Lewy Body Dementia can feel like from the inside. Medical understanding continues to evolve, and individual experiences may vary.

Printed in China

First edition

What This Book Is — And Is Not

This book is a practical companion written from lived experience. It explains patterns, risks, and responses that commonly occur in Lewy Body Dementia, using plain language and real-world examples.

It is not a diary, a timeline of decline, or a promise of recovery. It does not predict progression, replace medical care, or claim that one person's experience applies to everyone.

This book is intended as a safety and understanding anchor. Later volumes may be more personal, chronological, or reflective. This book exists to reduce confusion, prevent harm, and help people respond more gently and safely to what is likely happening.

Introduction

My name is Malcolm.

I am living with Lewy Body Dementia (also known as Dementia with Lewy Bodies).

When I was diagnosed, I looked for something simple and human that explained what this illness actually feels like — not just what it looks like from the outside. I found medical descriptions, checklists, and statistics. What I didn't find was a voice that sounded like mine.

This book exists because of that gap.

Lewy Body Dementia does not behave neatly. It fluctuates. It hides. It contradicts itself. On some days I can think clearly and function well. On other days, the fog is thick, my energy collapses, and simple tasks become overwhelming. These shifts are real, neurological, and often misunderstood.

I have written this book to do three things:

- to describe what Lewy Body Dementia can feel like from the inside
- to offer practical guidance that improves safety and day-to-day living
- to reduce confusion, guilt, and fear for both patients and carers

This is not a medical textbook.

It is not a diary.

And it is not a promise of answers.

It is a companion — written slowly, carefully, and honestly — for people navigating something that rarely follows rules.

If you are living with Lewy Body Dementia, I hope this book helps you feel less alone.

If you are caring for someone with Lewy Body Dementia, I hope it helps you recognise patterns that are often invisible and understand that much of what you are seeing is not deliberate, psychological, or within anyone's control.

A short guide on how to use this book appears on the next page.

How To Use This Book

This book is not meant to be read all at once.

Lewy Body Dementia affects attention, energy, memory, and emotional tolerance. Some days you may be able to read several pages. Other days, a paragraph may be enough. Both are okay.

You can read this book in order, or you can dip in and out. The chapters stand on their own. The appendices are designed to be used as needed.

If you are living with Lewy Body Dementia:

- Read what feels manageable.
- Skip anything that feels overwhelming.
- The practical sections are there to support safety and daily living.
- The optional journal excerpts exist only if you want recognition, not obligation.

If you are a carer, partner, or family member:

- You may want to start with the Quick Reference and Medical Safety & Red Flags appendices.
- These sections highlight patterns that are often misunderstood or missed.
- Not everything will apply all the time. This illness is variable.

About the appendices:

- Appendix A — Selected Journal Excerpts (Optional)
  Short lived-experience excerpts. These are not required reading. They exist to show what certain states can feel like from the inside.
- Appendix B — Medical Safety & Red Flags
  Information intended to support safer medical care. This section is especially relevant during hospital visits, medication changes, or emergencies.

A final note

This book does not replace medical care. It is one perspective, written from lived experience and supported by trusted medical sources. Its purpose is to reduce confusion, increase safety, and remind you that what you are experiencing is not imagined.

Use this book the way you need to.

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Introduction: Before The Fog

Before Lewy Body Dementia entered my life, I was already someone who lived inside systems — mechanical ones, logical ones, creative ones. My brain was never a quiet place, but it was a productive one.

I was born in Blenheim, New Zealand, after my parents returned from working in Fiji. My older brother was born overseas, my sister later in Christchurch, where I did most of my growing up. From early childhood, I was the creative middle child — the one who didn't quite fit the mould but kept building things anyway.

At preschool, I would sit under a tree and eat a cardboard box. At home, my mum brought home stacks of printed paper from her data-processing job, and I covered them with drawings. I didn't know it then, but I was already learning how to think visually, spatially, and creatively.

I loved construction sets. Cheap plastic knock-offs first, then real Technic LEGO — forklifts, gears, moving parts. Engineering excellence in miniature. I pulled things apart constantly, trying different designs just to see what would happen.

School was hard. I struggled with traditional learning, especially English and writing, but I loved logic. When I got my first computer — a Sinclair ZX Spectrum — everything changed. Programming felt like LEGO for the mind.

Once the memory upgrade arrived, I even created my own computer language, complete with an editor and compiler. I finally understood how my brain worked: give me logic, structure, and freedom, and I would fly.

I became an electrician because wiring, motors, and switches followed rules that made sense. I spent years in continual education, learning how systems fit together. Around the same time, someone showed me how to juggle stones in a ditch. I was terrible at first. I dropped everything. But I kept going, and eventually something clicked.

Juggling led to invention. I put batteries and LEDs inside balls so I could see light trails at night. Prototypes turned into products. Products turned into a business. Eventually, that became *Home of Poi — a company built on creativity, persistence, and the belief that anyone can learn if they're willing to give it a try.

I was driven by helping people, by community service, by teaching skills that built confidence. I joined service groups, mentored others, and learned the hard way that caring for everyone except yourself eventually comes at a cost.

This matters, because when Lewy Body Dementia arrived, it didn't just take memory. It attacked a brain that had been trained for decades to build, reason, invent, and adapt. What followed wasn't simply forgetting — it was the slow loss of a system that once worked beautifully.

** Home of Poi, www.homeofpoi.com*

A Communication Guide

Communication difficulties in Lewy Body Dementia are often misunderstood.

They are not primarily about memory.

They are about processing.

Long before words disappear, the ability to receive, filter, and respond to information becomes unreliable. This can make conversations confusing, exhausting, or distressing — for everyone involved.

Understanding this early can prevent years of unnecessary conflict, shame, and hurt.

Communication fails before memory does.

In Lewy Body Dementia, the brain's ability to process incoming information fluctuates. Some moments are clear. Others are foggy or overloaded.

A person may hear you, but not process meaning.

They may understand later, not immediately.

They may respond incorrectly, not intentionally.

They may shut down to protect themselves.

These are capacity issues, not attitude problems.

Processing delay is not refusal.

Silence is often thinking time, not avoidance.

Tone matters more than words.

When processing is impaired, emotional tone is often received before language. A calm voice reassures. A sharp tone escalates distress instantly.

Questions increase cognitive load.

Multiple questions feel like an interrogation.

Statements and reassurance reduce load.

Corrections feel like attacks.

If a correction does not affect safety or dignity, let it go.

Arguments fail because capacity is gone.

Pause first. Revisit later — or not at all.

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Repetition is not manipulation.

It is anxiety or incomplete processing looping.

Silence can be supportive.

Presence can be enough.

Helpful phrases:

- “You’re safe.”
- “I’m here.”
- “We can do this later.”
- “There’s no rush.”

Phrases that often make things worse:

- “You already asked that.”
- “Just calm down.”
- “You were fine earlier.”

If communication feels difficult, it is not because the person has become difficult.

It is because the brain is working harder than it should have to.

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When The Brain Stops Being Reliable

The Day My Brain Stopped Being Reliable

The clinical patterns described here are consistent with established diagnostic criteria and research; see the Medical and Scientific References section.

Lewy Body Dementia doesn't arrive like a stroke. There is no single dramatic moment where everything breaks. It arrives quietly, then repeatedly, until you realise something fundamental has changed.

For me, the first real sign wasn't memory loss.

It was unreliability.

My brain still worked — brilliantly at times — but I could no longer trust when it would work, or for how long. Some days I felt sharp, clear, almost cured. Other days, simple tasks collapsed me into bed like I'd pulled the power cord on a computer.

This unpredictability is one of the cruelest parts of Lewy Body Dementia. It tricks you. It convinces you that if you just try harder, rest less, push more, you'll get back to where you were previously.

You won't.

Not because you're weak.

But because the system itself is failing intermittently.

Understanding this early matters. It can save you years of guilt, self-blame, and pointless fighting.

Brain Crashes — What They Are And What They Are Not

A brain crash is **not** tiredness.

It is **not** laziness.

It is **not** depression.

And it is **not** something you can “push through” safely.

A brain crash happens when too many systems overload at once.

Sound, light, emotion, thought, movement — they all arrive together, and the brain loses its ability to filter. Imagine every radio station playing at once, full volume, through a single speaker inside your skull.

When this happens, the brain pulls the emergency brake.

Symptoms of a brain crash can include:

- sudden overwhelming fatigue
- inability to think or speak properly
- clumsiness or loss of coordination
- shallow or disrupted breathing
- panic or a sense of imminent danger
- an irresistible need to lie down immediately

From the outside, it can look like:

- giving up
- shutting down
- being dramatic

From the inside, it feels like system failure.

The most important thing to understand is this

A brain crash is the brain protecting itself.

When it happens, the safest response is:

- reduce stimulation
- reduce demands
- rest

Anything else makes the crash deeper and longer.

When terms like “crash,” “shutdown,” or “micro-seizure” are used here, they describe lived experience and observable effects, not a formal medical diagnosis unless explicitly stated by a clinician.

The “Foggy Brain” State

Not all bad days are crashes.

Sometimes the brain doesn’t shut down — it just slows and clouds over. This is what I call foggy brain.

In this state:

- thoughts are hazy and hard to hold
- words take effort to retrieve
- concentration drifts
- decision-making becomes exhausting

You’re awake. You’re functional. But everything takes three times the effort for half the result.

This is where people get into trouble.

Because from the outside, foggy brain looks like:

- “You’re doing fine”
- “You seem okay now”
- “You were better earlier”

From the inside, it feels like trying to move forward in thick fog while being told to hurry up.

Foggy brain days require:

- slower pace
- fewer decisions
- simplified tasks
- kindness toward yourself

They are not days for fixing complex problems, having hard conversations, or proving anything to anyone.

Micro-Seizures And Memory Loss In Real Time

When I become overtired or overstimulated, my brain can suddenly shut down for a few seconds. These episodes are brief, often unnoticed by others, and don't look like the seizures people expect. I call them micro-seizures — not as a formal diagnosis, but as a way to describe how these brief shutdowns feel and behave from the inside.

The best way I can describe them is as a computer crash.

While I am thinking, talking, or writing, my brain abruptly stops. There is no warning and no gradual fade-out. Whatever I was doing at that exact moment does not get saved. When my brain restarts seconds later, I may still be sitting upright with my eyes open, but the recent events are gone.

I often know that something has failed, but not what it was.

For example, I might be writing a sentence and stop halfway through a word. When I come back, I can see the partial sentence on the screen, but I have no memory of what I was trying to say or why. If I try to continue, another crash can occur within seconds, wiping the new attempt as well. After several of these rapid resets, my brain usually forces a full shutdown and I fall into deep sleep.

This is not ordinary forgetfulness. It is not distraction, and it is not simply being tired. It is a momentary loss of the brain's ability to maintain continuity — a failure to carry short-term information across time.

From the outside, I may appear awake. From the inside, it feels like my mind has blinked.

These episodes explain why parts of my journal contain unfinished sentences, repeated phrases, or sudden endings such as "Goodnight" appearing without context. The writing is not careless; it is interrupted. The memory that would normally link one moment to the next never gets written.

Understanding this has helped me — and those around me — stop misinterpreting these events as lack of effort, poor attention, or confusion. They are mechanical failures in a damaged system doing its best to keep running.

Clinical note

Brief non-convulsive seizure activity and transient lapses in awareness have been reported in Lewy Body Dementia and related neurodegenerative conditions. These episodes may involve disrupted thalamocortical signalling, leading to sudden interruption of consciousness or memory encoding without outward convulsive signs. Formal diagnosis may require EEG monitoring, though short-lived events are often difficult to capture.

(See Appendix A: Micro-Seizure With Loss of Recent Memory, p. 100.)

Neuroplasticity & Adaptation (Plain English)

Lewy Body Dementia damages brain networks over time, but the brain is not static.

It has a limited ability to adapt, re-route, and compensate — a process known as neuroplasticity.

Neuroplasticity Does Not Mean The Disease Is Reversed Or Cured.

It means that other brain areas may partially take over tasks that have become unreliable, especially when demands are reduced and routines are stabilised.

In practical terms, this can look like:

- relearning a task that was temporarily lost
- developing a new way to do something familiar
- function improving after rest, routine, or reduced sensory load
- abilities returning unevenly rather than all at once

This adaptation is:

- slow
- fragile
- energy-dependent
- easily overwhelmed by stress, illness, or overload.

That is why pushing harder often makes things worse, not better.

Neuroplasticity works best when:

- the environment is calm and predictable
- tasks are simplified and repeated
- pressure to “perform” is removed
- rest is treated as part of recovery, not failure

Over time, these adaptations can preserve useful function, even as the disease continues underneath.

This is not false hope.

It is realistic hope, grounded in how damaged brains cope — not by fixing themselves, but by finding workarounds

See Care Protocols 1, 2, and 11 (p. 66, p. 70 and p. 82, reducing load to preserve function).

Sensory Overload & Environment

One of the biggest misunderstandings about Lewy Body Dementia is noise.

It’s not that sounds are louder.

It’s that the brain can no longer separate them.

A kettle boiling, a television playing, someone talking, a phone buzzing — once, your brain filtered these automatically. With Lewy Body Dementia, that filter breaks.

The result is audio stacking.

Everything arrives at once. Nothing gets priority.

When this happens:

- thinking collapses
- irritability spikes
- panic rises
- crashes become likely

Silence isn’t a luxury.

It’s medicine.

This is why people with Lewy Body Dementia:

- retreat to quiet rooms
- leave social situations suddenly
- seem antisocial

They are not avoiding people.

They are avoiding collapse.

Visual overload works the same way.

Supermarkets combine bright lights, movement, noise, signage, choice, and time pressure. The visual cortex becomes overwhelmed. Balance wobbles. Thinking slows. Anxiety rises.

This is not psychological weakness.

It is neurological overload.

Helpful adaptations include:

- shorter visits
- quieter times
- written lists
- having a support person
- leaving early without guilt

There is no prize for enduring suffering.

Environmental control is not avoidance.

It is survival.

Symptoms Without Warnings

Not Everything Comes With a Warning

Some things arrive quietly.

There isn’t always a build-up, a trigger, or a clear reason. One moment I’m functioning, the next I’m not. No panic, no drama — just a sudden drop.

From the outside, this can look suspicious. As if something must have caused it. As if the explanation is missing.

Often, it isn’t.

In Lewy Body Dementia, symptoms don’t always announce themselves. There isn’t always time to adapt or prepare. The change just happens, and I’m left dealing with the aftermath.

This unpredictability is exhausting. It means I can’t promise consistency, and I can’t always explain what just went wrong.

Sudden doesn’t mean imagined.
And unexplained doesn’t mean untrue.

Once this was understood, fewer questions were asked — and that, in itself, made things easier.

Explaining Costs Energy

Explaining Is Work

When something goes wrong, people want to understand it.

That’s reasonable. But explaining what’s happening inside my head uses the same systems that are already failing. The words, the sequencing, the memory — they all come from the same place that’s struggling.

Sometimes, answering questions makes things worse.

It’s not that I don’t want to explain. It’s that explaining costs energy I may not have. And once it’s gone, there’s no getting it back quickly.

This is why I write things down. Why I rely on routines, notes, and protocols. Not to avoid conversation — but to survive it.

Silence doesn’t mean nothing is happening.

It often means too much already has.

Hallucinations & Misinterpretation

Hallucinations are one of the most misunderstood and frightening features of Lewy Body Dementia — both for the person experiencing them and for those around them.

In Lewy Body Dementia, hallucinations are not a sign of imagination, attention-seeking, or loss of sanity. They are a neurological symptom caused by disrupted visual processing, attention, and reality-filtering systems in the brain.

What Hallucinations Are Like In LBD

Most hallucinations in Lewy Body Dementia are visual, though other senses can be involved.

Common experiences include:

- Seeing people, animals, or objects that are not there
- Misinterpreting shadows, patterns, or reflections as something real
- Seeing movement where none exists
- Brief, vivid images that appear fully formed and detailed

These experiences can occur early in the illness, sometimes years before a diagnosis is made.

They may:

- come and go unpredictably
- worsen with fatigue, illness, infection, or stress
- increase during low light, poor sleep, or sensory overload

Importantly, the person may:

- recognise the hallucination is not real
- be unsure whether it is real
- or believe it is real in the moment

This can fluctuate — even within the same day.

Hallucinations Vs Misinterpretation

Not everything that looks like a hallucination actually is one.

In Lewy Body Dementia, the brain may:

- fail to correctly interpret visual information
- fill in missing details incorrectly
- confuse perception with memory

This leads to misinterpretation, such as:

- mistaking a coat for a person
- interpreting a shadow as an animal
- seeing patterns where none exist

continued on next page...

Misinterpretations are often worsened by poor lighting, clutter, or visual complexity.

Why Hallucinations Happen In LBD

Hallucinations in Lewy Body Dementia are linked to:

- impaired visual processing pathways
- disrupted attention and alertness systems
- altered neurotransmitter balance (especially acetylcholine and dopamine)

They are not a psychological problem and are not under voluntary control.

How Hallucinations Affect The Person

Even when hallucinations are not frightening, they can be:

- confusing
- exhausting
- emotionally unsettling

Some people describe:

- questioning their own reality
- feeling embarrassed or afraid to talk about it
- being dismissed or misunderstood by others
- This silence often makes the experience worse.

How Carers And Others Can Respond

When hallucinations occur:

- Arguing rarely helps
- Confrontation can increase distress
- Dismissing the experience can damage trust

Often the most helpful response is:

- calm reassurance
- gentle redirection
- reducing visual or sensory load

Medication is not always the best first response, especially in Lewy Body Dementia, where many antipsychotics can cause severe harm.

continued on next page...

See: Care Protocol 3 — Sensory Overload / Shutdown
See: Care Protocol 9 — Medication Changes & Sensitivity

A Key Reassurance

Hallucinations in Lewy Body Dementia are:

- common
- neurological
- variable
- not a personal failure

They do not mean the person is “losing themselves”.

Understanding this reduces fear — for everyone involved.

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Sleep, Dreaming & The Night Brain

Sleep in Lewy Body Dementia is not restorative by default.

You can sleep for hours and still wake exhausted. Sleep may be fragmented, shallow, mistimed, or filled with vivid dreams.

This is not laziness.

It is neurological dysfunction.

Sleep becomes something the brain struggles to enter, stay in, and exit cleanly. Waking can trigger confusion, pain, fear, or a full brain crash. This is why mornings are often the worst part of the day.

For a long time, I barely dreamed. Then suddenly, REM sleep returned — vividly. This mattered.

REM sleep is when the brain processes emotion, consolidates memory, and resets certain circuits. Its return does not mean recovery, but it does mean something is still working.

Dreams in Lewy Body Dementia can be detailed, sequential, exhausting, and emotionally intense. They can blur into waking life, especially during transitions between sleep and wakefulness.

Understanding this helps carers avoid mislabelling dream-related confusion as hallucination or psychosis.

Another unsettling experience is visual activity when the eyes are closed — flashing lights, patterns, rapid colour movement. Opening the eyes stops it. Closing them brings it back.

This is not imagination.

It is the visual cortex misfiring when external input drops away.

Knowing this reduces fear. Not everything strange is dangerous. Some things are simply the brain struggling to regulate itself in the dark.

Autonomic Failure (Plain English)

Most people think dementia is about memory.

Lewy Body Dementia is different.

It attacks the systems you do not consciously control — the ones that keep you alive and balanced without thinking about them. These are called autonomic systems.

They include:

- breathing
- heart rate
- blood pressure
- digestion
- temperature regulation
- sweating
- sleep–wake cycles

When these systems malfunction, the body feels unpredictable and unsafe, even when nothing obvious is wrong. This is why people with Lewy Body Dementia often say, “Something feels wrong, but I can’t explain it.”

Breathing can feel shallow or manual, as if you have to think about every breath. Heart rate and blood pressure can swing without warning. Standing may cause dizziness. Lying flat may feel unsafe. Mornings are often the worst part of the day.

From the outside, this can look like anxiety.

From the inside, it feels like control slipping away.

Reassurance helps more than logic.

Telling someone their readings are fine does not fix a nervous system that is misfiring. Calm presence helps more than explanation.

The gut is one of the hardest-hit systems.

Digestion slows. Motility becomes unreliable. Constipation becomes chronic. This is neurological, not dietary failure.

When the gut stalls, pressure builds, pain increases, appetite drops, thinking worsens, and brain crashes become more likely. Managing digestion is not about comfort — it is about keeping the brain functional.

continued on next page...

Temperature regulation also becomes unreliable.

One moment you are sweating, the next you are freezing. Clothing that felt fine an hour ago suddenly feels unbearable.

This is not fussiness.

It is faulty regulation.

Stress is the great amplifier.

When stress rises, autonomic systems destabilise, sensory overload increases, crashes happen faster, and recovery takes longer.

Stress does not motivate a Lewy brain.

It short-circuits it.

Involuntary Muscle Spasms & Jerks (Plain English)

Uncontrollable muscle spasms, jerks, or sudden tightening can occur in Lewy Body Dementia. They are often brief, unpredictable, and unsettling — especially when the person is awake and aware.

These movements are not deliberate, not behavioural, and not emotional outbursts. They are the result of misfiring signals in a nervous system that is struggling to regulate itself.

People describe these episodes in different ways:

- sudden jerks of an arm, leg, or shoulder
- repeated twitching or spasms
- muscles tightening or pulling without warning
- brief, shock-like movements when overtired or stressed

They may happen:

- during fatigue or sensory overload
- as part of a brain crash or shortly before one
- on waking or during low-arousal states
- after illness, poor sleep, or medication changes

From the outside, these movements can look alarming.

From the inside, they often feel mechanical — like the body has received the wrong instruction and acted on it before the brain could intervene.

continued on next page...

These spasms are not the same as epileptic seizures. The person is usually conscious, aware, and able to remember what happened. They also differ from anxiety tremor or voluntary movement. They sit in the grey area where motor control, autonomic regulation, and sensory overload overlap.

What helps:

- reducing stimulation (sound, light, conversation)
- allowing rest without pressure
- calm reassurance rather than restraint
- noticing patterns (fatigue, stress, time of day)

What makes them worse:

- rushing
- confrontation
- repeated questioning
- insisting the person “relax” or “stop it”

These movements are frightening but not usually dangerous on their own. The risk comes from falls, exhaustion, or escalation caused by panic or misunderstanding.

Important safety note

Seek medical advice if involuntary movements are:

- new, sudden, or rapidly worsening
- accompanied by collapse, loss of consciousness, or injury
- clearly linked to a recent medication change
- persistent, painful, or causing repeated falls

(See Appendix B — Medical Safety & Red Flags, p. 106, and Care Protocol 8: Autonomic Episodes, p. 78)

Understanding that these movements are neurological misfires, not emotional or intentional behaviour, reduces fear and helps everyone respond more safely.

Clinical footnote

In Lewy Body Dementia, involuntary muscle jerks or spasms may reflect disrupted motor control and autonomic regulation, including impaired basal ganglia function and unstable neurotransmitter signalling. Similar phenomena have been described in LBD and related synucleinopathies as myoclonus, dystonia, or stress-triggered motor activation. These movements are often non-epileptic, occur without loss of consciousness, and may fluctuate with fatigue, illness, or medication sensitivity. Clinical assessment is warranted if symptoms are new, progressive, or associated with injury, collapse, or medication changes.

Adrenaline, Crashes & False Recovery

Sometimes something strange happens.

Pain, shock, urgency, or sudden fear — and the brain seems to wake up. Focus sharpens. Energy appears. For a short time, everything feels clearer.

This is adrenaline.

Adrenaline is the body's emergency power supply. It does not repair the system — it bypasses it. When it floods the body, survival becomes the only priority. Background noise drops away. Filtering briefly improves.

This can stop a brain crash mid-flow or delay it entirely. It can look like recovery.

It is not recovery.

Adrenaline burns fuel fast. Once it fades, dopamine and acetylcholine drop again. Fatigue hits hard. The crash that follows is often worse than the original one.

This is why stressful "good days" are often followed by terrible next days. It is why pushing through feels punished later.

Repeatedly relying on adrenaline is like jump-starting a failing battery again and again. It works — until it doesn't.

Feeling capable does not mean being safe.

Respecting limits matters even when you feel clear.

Rest Is Not Recovery

Sleeping Is Not a Reset Button

When my brain crashes, I sleep.

Sometimes for an hour. Sometimes for much longer. From the outside, it looks like rest should fix things. Like charging a flat battery.

But sleep doesn’t restore me to how I was before.

Rest helps me avoid getting worse. It stops the overload from tipping into something more serious. It gives the system a chance to cool down. But it doesn’t rebuild what’s already been lost.

I don’t wake up “repaired”.

Some days I wake up clearer. Some days I don’t. And there’s no reliable way to predict which it will be.

Sleeping is not a reset button — it’s damage control.

This matters, because people often wait for rest to work like it used to. They expect improvement, and when it doesn’t come, they assume something went wrong.

Nothing went wrong.

Rest did what it can do now. No more, no less.

Once I stopped expecting sleep to restore me, I could use it properly — as protection, not as a cure.

Clarity Can Be A Trap

When Feeling Better Is Dangerous

Sometimes I wake up and feel almost normal.

My head is clear. My body responds. I can talk, plan, even do things that were impossible the day before. These moments feel like relief. Like progress.

They are not the same as safety.

When clarity returns, it's tempting — for me and for others — to make the most of it. To catch up. To push. To believe the bad days are behind me.

That's often when the worst crashes happen.

A clear moment doesn't mean the system is stable. It just means it's coping for now. Using it heavily can drain what little reserve is left, and the cost shows up later — sometimes hours, sometimes the next day.

This is one of the cruel tricks of Lewy Body Dementia. It offers just enough clarity to invite overuse.

Learning to stop while things still feel okay goes against instinct.
But it’s often the only way to avoid a bigger collapse.

Feeling better doesn’t mean I can do more.
It often means I need to do less.

Emotions, Frustration & Anger

Anger in Lewy Body Dementia is rarely about the topic at hand.

It usually begins with overload. When thinking becomes difficult, frustration rises. When frustration is not relieved, anger appears.

This is not a personality change.

It is capacity collapse.

When the brain is overloaded, reasoning shuts down and emotional circuits take over. Language becomes unreliable. Trying to explain, correct, or argue during this phase almost always makes things worse.

Logic arrives too late.

What helps is not winning an argument, but lowering demand. Slowing the environment. Reducing noise. Allowing retreat.

Helpful phrases include:

- “We can talk about this later.”
- “You’re safe.”
- “I’m here.”
- “Let’s pause.”

Unhelpful phrases include:

- “You’re wrong.”
- “Calm down.”
- “You always do this.”

De-escalation is not giving in.

It is protecting the brain.

It prevents deeper crashes and preserves trust.

Caregiver Survival & Relationships

Lewy Body Dementia does not only affect the person who has it. It reshapes the relationship around them.

One of the hardest truths for carers is this: the person you love is still there, but they are not consistently accessible. Some days they feel familiar. Other days they feel distant or altered. The constant fluctuation resets hope again and again, and that is exhausting.

Many carers experience grief while still caring. This is known as ambiguous loss — the person is present, but not fully. Naming this matters. It allows grief without guilt.

For the person with Lewy Body Dementia, there is another quiet pain: still being relied on while capacity is declining. Being needed can feel like pressure. Pressure leads to overexertion. Overexertion accelerates crashes and decline.

Reducing expectations is not giving up.

It is protective.

Worth is not measured by output.

Many people with Lewy Body Dementia worry deeply about being a burden. They think about the future constantly — how others will cope, what will be left unfinished, who will struggle when they are gone. These thoughts are loving, but heavy.

Gentle grounding helps:

- “Today is enough.”
- “Right now is okay.”

Illness can slowly turn partners into managers, nurses, or supervisors. When this happens, intimacy can erode. Protecting the relationship requires intentional softness: touch without task, shared quiet, humour, and moments that are not about care.

Love must be allowed to exist alongside illness,
not replaced by it.

Connection, Intimacy, And Cognitive Regulation

Safe, consensual intimacy — including sexual intimacy — can support emotional regulation, orientation, and cognitive engagement in some people living with Lewy Body Dementia.

For some couples this may include sexual activity; for others it may involve touch, closeness, or quiet shared connection. Such connection can help maintain mood, identity, and reduce anxiety or isolation.

Capacity, comfort, and consent are essential and may fluctuate. Intimacy should never be pressured and may be limited by fatigue, medication effects, autonomic symptoms, or confusion.

For medical and ethical context, see Appendix — Medical and Scientific References: Rosetti & Basson (2025); Wright et al. (2019).

Medical Reality (Checked & Grounded)

⚠️ HIGH RISK CONDITION — LEWY BODY DEMENTIA

People with Lewy Body Dementia can be extremely sensitive to medications, anaesthesia, and physiological stress.

Some routine treatments may cause severe or lasting harm.

Lewy Body Dementia disrupts two critical neurotransmitters: dopamine and acetylcholine.

These chemicals help regulate movement, attention, perception, and the brain's ability to filter incoming information.

When these systems falter, the brain struggles to prioritise signals. Background noise becomes foreground chaos. Important information gets lost. This contributes to fluctuations, hallucinations, brain crashes, and extreme sensitivity to medication.

The thalamus acts like a traffic controller for sensory input. In Lewy Body Dementia, that controller becomes unreliable. Too many signals are waved through at once, while others are missed entirely. The result is overload, confusion, panic, and shutdown.

This means regulation is failing.
Many people react badly to drugs that are otherwise considered standard, especially antipsychotics and sedatives.

Reactions can include:

- severe confusion
- rigidity
- collapse
- long-lasting decline

Medication changes must be slow, cautious, and closely monitored.

What is safe for other conditions may be dangerous here.

Lewy Body Dementia is often confused with Parkinson's disease or Alzheimer's disease. While they share features, Lewy Body Dementia typically involves earlier hallucinations, stronger fluctuations, greater autonomic involvement, and higher medication sensitivity. Misdiagnosis is common.

When Lewy Body Dementia occurs alongside other conditions, such as diabetes, complexity increases. Low blood sugar can mimic brain crashes or confusion. Lewy-related cognitive changes can impair awareness of symptoms and recovery cues. Managing one condition without considering the other can be unsafe.

This section is not a substitute for medical advice.

It exists to help patients, carers, and clinicians communicate more clearly and reduce preventable harm.

Why Yesterday Doesn’t Predict Today

Yesterday, I was fine.

Or at least, I looked fine.

I woke up, talked, moved around, even got a few things done. To anyone watching — including me — it might have looked like I was improving. Like whatever had gone wrong the day before had passed.

But today is different.

That’s one of the hardest things about living with Lewy Body Dementia: the brain doesn’t move forward in a straight line. It doesn’t steadily decline, and it doesn’t steadily recover either. Instead, it fluctuates. It wobbles. It surprises you.

A “good day” doesn’t mean the system is fixed. It just means that, for a while, enough of the right switches lined up to let things run more smoothly. The wiring underneath hasn’t changed.

This is where people — carers, clinicians, and sometimes even me — get caught out.

Yesterday becomes the new expectation.
“If you could do it yesterday, why not today?”
“If you were fine this morning, what happened this afternoon?”

Nothing *happened*.

Nothing obvious broke.

The capacity just isn’t there anymore — not reliably, not on demand.

My brain can wake up clear, focused, and steady, then lose that clarity an hour later without warning. It can manage conversation in the morning and fail at simple tasks by lunchtime. It can hold things together long enough to give false reassurance, then quietly let go.

This doesn’t mean I wasn’t trying.
And it doesn’t mean anyone missed something.

It simply means that yesterday is not a baseline.

In Lewy Body Dementia, **today stands on its own**.
Plans need to stay soft. Expectations need room to move. And success has to be measured in moments, not comparisons.

Once I stopped judging today by yesterday, things made a little more sense — even when they were still hard.

Effort ≠ Capacity

Trying Harder Doesn’t Give Me More Brain

I am trying.

That part often gets missed.

From the outside, it can look like I’ve stopped, slowed down, or given up.

But inside, the effort is still there. Sometimes it’s even greater than before. The difference is that effort no longer guarantees results.

There was a time when pushing a little harder helped. If something was difficult, I could concentrate more, dig in, or take my time and get through it. That link has broken.

Now, effort and outcome are no longer connected.

I can put everything I have into a task and still fail at it. Not because I didn’t care, and not because I didn’t try — but because the capacity simply isn’t there in that moment. The circuits don’t respond, no matter how much I want them to.

This is one of the most frustrating parts of Lewy Body Dementia. The will to do something can still be strong, even when the ability has quietly slipped away.

Trying harder doesn’t create more brain.

It just uses up what little energy is left.

Once I understood this, I stopped blaming myself quite so much — and I stopped letting others measure my effort by my results

Meaning, Faith & Identity

Serious illness challenges identity. When your life has been built around thinking, creating, fixing, helping, or providing, losing those abilities can feel like losing yourself.

But worth does not disappear with function.

You are not your output.

Faith and meaning can be sources of comfort, or sources of harm, depending on how they are framed. This book rejects blame-based faith, miracle pressure, and the idea that suffering means failure.

It embraces presence, compassion, and meaning without denial.

Faith should reduce suffering, not increase it.

Purpose does not vanish as capacity changes.

It transforms.

Sometimes purpose looks like rest.

Sometimes it looks like receiving care.

Sometimes it looks like being present rather than productive.

That is not giving up.

It is adaptation.

Living well with Lewy Body Dementia is not about pretending things are fine. It is about meeting reality honestly, gently, and with as much dignity as possible.

Care Protocols (Practical Use)

(For carers, clinicians, and crisis moments)

These protocols describe observable patterns and safe responses. They are not diagnostic tools and do not replace clinical assessment.

Quick Start — Which Section Do I Need Right Now?

Use this page if things are happening quickly and you are not sure where to start. You do not need to read everything — just find the situation that best matches what is happening right now.

START HERE — QUICK TRIAGE

If the person is **suddenly confused**, **panicked**, or **overwhelmed**

→ See Protocol 1: During a Brain Crash

If today feels **foggy** but they are still functioning

→ See Protocol 2: Foggy Brain Day

If noise, light, crowds, or conversation are **causing shutdown**

→ See Protocol 3: Sensory Overload / Shutdown

If **confusion** or **distress** happens **on waking** or first thing in the morning

→ See Protocol 4: Waking Confusion / Morning Crash

If **sleep** is broken, **dreams** are intense, or **nights** are chaotic

→ *See Protocol 5: Sleep Disruption & REM Nights*

If there is a **sudden burst** of energy followed by a **rapid crash**

→ *See Protocol 6: Adrenaline "False Recovery"*

If **anger**, **agitation**, or **emotional** escalation is building

→ *See Protocol 7: Anger / Escalation*

If symptoms involve **blood pressure**, **heart rate**, **sweating**, **digestion**, or **faintness**

→ *See Protocol 8: Autonomic Episodes*

If **medications** have changed or **reactions** seem unusual

→ *See Protocol 9: Medication Changes & Sensitivity*

If **you are unsure** whether to push on, stop, rest, or seek help

→ *See Protocol 10: When To Stop, Rest, Or Seek Help*

If visual clutter, reading, or concentration is making things worse

→ *See Protocol 11: Visual & Cognitive Load Aids*

If **medical procedures**, **sedation**, or **surgery** are being discussed

→ *See Protocol 12: Anaesthesia, Surgery & Procedures*

If in doubt, start with Protocol 1 and work slowly.

Protocol 1: During A Brain Crash

What you may notice

- sudden overwhelming fatigue
- inability to think, speak, or respond clearly
- clumsiness or loss of coordination
- shallow, irregular, or manual-feeling breathing
- panic or a sense of imminent danger
- an urgent need to lie down or withdraw

Sudden changes are not always predictable or preventable (*see Symptoms without Warnings, p. 30*).

What is likely happening (plain English)

A brain crash occurs when too many signals overload the brain at once. Sensory input, emotion, thought, and physical demands arrive together, and the brain loses its ability to filter them.

This is not failure.

It is the brain activating its circuit breaker to protect itself.

What helps:

- reduce stimulation immediately
- remove demands and decisions
- allow rest or withdrawal without guilt
- calm presence and reassurance

What makes it worse:

- noise, questioning, urgency
- pressure to explain or continue

After the Crash: The Recovery Window

A brain crash does not end when alertness returns.
Recovery occurs in stages and may take hours or days.

During this window, the person may appear functional but remains neurologically fragile. The brain is stabilising, not restored.

Pushing activity, decision-making, or stimulation too early frequently deepens or prolongs the crash.

Explaining symptoms uses the same strained systems as thinking itself (*see Explaining Costs Energy, p. 31*).

Rest during this phase is not avoidance.
It is part of recovery.

Rest helps prevent further overload but does not restore lost capacity (*see Rest Is Not Recovery, p. 48*).

continued on next page...

Effort does not reliably translate into capacity (*see Effort ≠ Capacity, p. 60*).

Important notes

- Recovery time varies.
- Apparent improvement does not mean resilience has returned.
- Pushing during the recovery window almost always deepens or prolongs the crash.

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Scan the QR code to view

available formats and ordering options.

Protocol 2: Foggy Brain Day

What you may notice:

- slowed thinking
- word-finding difficulty
- fatigue with simple tasks
- indecision
- sensory sensitivity

What is likely happening

The brain is still functioning, but clarity and processing speed are reduced.

Decision freeze (not defiance)

On foggy brain days, the ability to initiate or sequence decisions may temporarily fail, even when understanding is intact.

This can look like indecision, avoidance, or resistance, but it is a neurological lock — not unwillingness.

Offering fewer choices, slowing the pace, or postponing decisions often reduces distress more effectively than encouragement or pressure.

What helps:

- slow pace
- fewer decisions
- short, single-step tasks
- validation of effort

What makes it worse:

- rushing
- multitasking
- comparisons to “better days”

Effort does not reliably translate into capacity (*see Effort ≠ Capacity, p. 60*).

Explaining symptoms uses the same strained systems as thinking itself (*see Explaining Costs Energy, p. 31*).

Important notes

Gentle handling can prevent escalation into a crash.

Protocol 3: Sensory Overload / Shutdown

What you may notice:

- irritability or distress
- withdrawal
- urge to leave
- escalation toward crash

Sudden changes are not always predictable or preventable (*see Symptoms without Warnings, p. 30*).

What is likely happening

The brain cannot filter incoming stimulation.

Social and visitor load

Conversation, visitors, and emotional engagement carry cognitive and sensory load — even when they feel pleasant.

On vulnerable days, social interaction can trigger delayed overload or a later crash. Short, quiet contact is often safer than prolonged engagement.

Declining visits or leaving early is a protective strategy, not a social failure.

What helps:

- remove from environment
- reduce sound and light
- allow silence

Effort does not reliably translate into capacity (*see Effort ≠ Capacity, p. 60*).

Explaining symptoms uses the same strained systems as thinking itself (*see Explaining Costs Energy, p. 31*).

Important notes

Early exit is prevention, not failure.

Protocol 4: Waking Confusion / Morning Crash

What you may notice:

- confusion on waking
- fear or distress
- headache
- rapid fatigue

Sudden changes are not always predictable or preventable (*see Symptoms without Warnings, p. 30*).

What is likely happening

Sleep–wake transitions overload fragile systems.

What helps

- slow waking
- dim light
- reassurance
- permission to rest

Effort does not reliably translate into capacity (*see see Effort ≠ Capacity, p. 60*).

Morning clarity does not predict the rest of the day (*see Why Yesterday Doesn't Predict Today, p. 58*)

Important note

Protecting mornings protects the entire day.

Protocol 5: Sleep Disruption & Rem Nights

What you may notice:

- vivid dreams
- confusion on waking
- fear of sleep
- exhaustion

What is likely happening

Sleep architecture is disrupted.

What helps:

- gentle orientation
- predictable routines
- calm reassurance

Important note

Sleep quality affects all other symptoms.

Protocol 6: Adrenaline “False Recovery”

What you may notice:

- sudden clarity after stress
- overactivity
- severe crash later

Sudden changes are not always predictable or preventable (*see Symptoms without Warnings, p. 30*).

Periods of clarity do not indicate stability and may require extra caution (*see Clarity Can Be a Trap, p. 60*).

What is likely happening

Adrenaline bypasses failing systems temporarily.

What helps:

- rest despite clarity
- limit activity

Important note

Energy does not equal safety.

Protocol 7: Anger / Escalation

What you may notice:

- sudden anger
- raised voice
- refusal
- agitation

What is likely happening

Overload shifts control from reasoning circuits to emotional circuits. Language and logic become unreliable.

What helps:

- pause the interaction
- reduce demands
- lower sensory input
- calm reassurance

What makes it worse:

- arguing
- correcting
- insisting on resolution

Important note

De-escalation protects both the brain and the relationship.

Protocol 8: Autonomic Episodes

What you may notice:

- breathing difficulty
- dizziness
- gut discomfort
- temperature swings
- sudden weakness

Sudden changes are not always predictable or preventable (*see Symptoms without Warnings, p. 30*).

What is likely happening

Automatic bodily systems misfire.

What helps:

- stop activity
- allow sitting or lying down
- slow position changes
- reassurance

Effort does not reliably translate into capacity (*see Effort ≠ Capacity, p. 60*).

Important note

Symptoms are real even if tests appear normal.

Protocol 9: Medication Changes & Sensitivity

What you may notice:

- sudden confusion
- rigidity
- collapse
- rapid or lasting decline

What is likely happening

People with Lewy Body Dementia have heightened medication sensitivity.

What helps:

- slow medication changes
- careful monitoring
- clear communication with clinicians

Important note

Always flag Lewy Body Dementia before prescribing or procedures.

Protocol 10: When To Stop, Rest, Or Seek Help

For medical red flags and hospital-level risks,
see Appendix B, p. 106 — Medical Safety & Red Flags

🚑 **SEEK URGENT MEDICAL HELP IF ANY OF THE FOLLOWING ARE PRESENT:**

- chest pain
- collapse
- breathing difficulty
- sudden weakness
- rapidly worsening confusion

Important note

Stopping activity is care. Trust pattern changes.

Information to give paramedics

If help is required, clearly state:

- Diagnosis: Lewy Body Dementia
- Known medication sensitivities
- Recent medication changes
- Diabetes status (if applicable)
- What you observed and tried
- Other medical conditions ...

Sudden changes are not always predictable or preventable (*see Symptoms without Warnings, p. 30*).

Protocol 11: Visual & Cognitive Load Aids

(Bucket Hat, Anti-Fatigue Glasses)

What you may notice:

- visual overwhelm
- dizziness in busy spaces
- increased tripping or misjudging hazards
- improved stability when visual input is reduced

What is likely happening

The brain struggles to filter visual input. Reducing incoming information lowers cognitive load.

What helps

Bucket hat:

- limits upward and peripheral visual input
- encourages floor-level focus
- can improve balance and hazard awareness

Anti-fatigue glasses:

- reduces light intensity
- can decrease visual fatigue
- can help during foggy brain or shopping

Evidence note (plain language):

- These aids can reduce visual and cognitive load in specific situations
- They may improve comfort and steadiness, but effects vary
- Use situationally, not continuously

Periods of clarity do not indicate stability and may require extra caution (*see Clarity Can Be a Trap, p. 60*).

Supporting evidence:

see Medical & Scientific References (Visual & Falls section).

Protocol 12: Anaesthesia, Surgery & Procedures

⚠️ HIGH RISK CONDITION — LEWY BODY DEMENTIA

People with Lewy Body Dementia can be extremely sensitive to medications, anaesthesia, and physiological stress.

Some routine treatments may cause severe or lasting harm.

Why this matters

People with Lewy Body Dementia are at high risk of prolonged or permanent decline after anaesthesia or heavy sedation.

What may happen:

- severe delirium
- worsening hallucinations or rigidity
- loss of function
- failure to return to baseline

What helps:

- clearly informing all clinicians of LBD
- questioning necessity of procedures
- minimising sedation
- avoiding high-risk medications
- close post-procedure monitoring

Important note

This protocol exists to reduce preventable harm.

Protocol 13: Waking From A Low Dopamine / Low Arousal State

⚠️ CORE RULE — SAFETY FIRST

This state can resemble medical emergencies.
Always assess safety first.

What this state can look like:

- Eyes open but not fully present
- Slow or absent responses
- Appears “stuck” between sleep and wakefulness
- Heavy body, minimal movement
- May last minutes or hours

Step 1: Check safety first (this step overrides all others)

Before attempting to wake the person, check:

- Breathing is present and not laboured
- Skin colour is normal (not blue or grey)
- Pulse is present and not extremely weak
- If the person has diabetes, check blood sugar if possible
- Note the time and any recent medication i.e. insulin

continued on next page...

If any of these are concerning, skip to When to seek urgent help, on next page.

Step 2: Gentle stimulation

Use calm, non-threatening input:

- Say their name clearly (do not shout)
- Light touch to hand, shoulder, or cheek
- Allow time between attempts

Avoid sudden noise, shaking, or panic.

Step 3: Simple communication

If there is partial response, use very simple cues:

- Yes/no questions
- Single-choice questions
- Familiar phrases

Some people can respond with minimal gestures or breath sounds before speech returns.

Step 4: Environmental cues

If tolerated, gently increase orientation:

- Open curtains or turn on soft lighting
- Play familiar, non-stimulating music
- Adjust room temperature (cooler often helps)

Stop if agitation or distress increases.

Step 5: Important safety rules:

- Do not shake roughly
- Do not give food, drink, or medication until fully awake and able to swallow safely
- Keep airways clear
- Sitting upright may help once safe

When to seek urgent medical help

Call emergency services if:

- There is no reliable response after several minutes
- Breathing is abnormal
- Pulse is weak or irregular
- Lips turn blue
- New jerking, seizure-like activity, or extreme stiffness appears

continued on next page...

- A new medication was started recently (especially sedatives or painkillers)
- Blood sugar is dangerously low and not responding
- You feel unsafe managing the situation alone

Information to give paramedics:

If help is required, clearly state:

- Diagnosis: Lewy Body Dementia
- Known medication sensitivities
- Recent medication changes
- Diabetes status (if applicable)
- What you observed and tried
- Other medical conditions ...

Important note

This protocol does not always work quickly.

Some low dopamine states resolve slowly over hours.

The goal is safe re-engagement, not forcing alertness.

If responsiveness worsens or any red flag symptoms appear, stop the protocol and follow Appendix B — Medical Safety & Red Flags immediately.

Closing Note

If this book helps you recognise what is likely happening, respond with more kindness, or feel less alone, then it has done its job.

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Appendix A — Selected Journal Excerpts (Optional)

Opening Note

This appendix contains carefully selected excerpts from my original journals (1,800+ pages) written during periods of neurological fog, cognitive crashes, emotional strain, and low-arousal states associated with Lewy Body Dementia.

The excerpts are not presented chronologically. They are intentionally brief and illustrative, chosen to reflect a range of experiences that can occur at different points in the illness — including later-stage patterns such as prolonged fatigue, slowed responsiveness, and reduced dopamine-driven activation.

These entries are optional. They are included to help readers and carers recognise patterns, validate lived experience, and understand how Lewy Body Dementia can feel from the inside — even when outward signs appear minimal or “stable.”

If you find this section distressing, it is safe to skip it.

Excerpt 1 — Before There Was A Name

I knew something wasn’t right, but I didn’t have words for it.

Not proper ones.

I could still talk. Still joke. Still function well enough that most people wouldn’t notice. That made it harder, not easier. When things go wrong quietly, you start doubting yourself.

I searched for explanations. I wanted something that sounded like me. What I found instead was medical language, timelines, and tidy descriptions that didn’t match what I was living.

What I needed wasn’t reassurance.

It was recognition.

Excerpt 2 — A Foggy But Functional Day

From the outside, this would have looked like a good day.

I managed to concentrate for a while. I wrote. I answered messages. I even felt briefly capable. But everything required deliberate effort, like holding something fragile together with both hands.

The fog never lifted. It just thinned enough to move through.

Afterwards, I collapsed. Not dramatically. Quietly. As if my system had used everything it had and then shut itself down.

Function came at a cost I couldn't see until it was paid.

Excerpt 3 — What I Mean By A "Brain Crash"

A brain crash isn't panic.

It isn't sadness.

It isn't anxiety.

It's like the power goes out in stages.

First the thinking slows. Sounds blur together. Light becomes too sharp. Words stop lining up properly. Then the effort of staying upright feels unreasonable, like gravity has been turned up.

I don't fall apart.

I disappear inward.

There's no warning buzzer. No countdown. Just a sudden, undeniable limit.

Once it happens, there is no pushing through. The system has decided. Recovery isn't measured in minutes. Sometimes it's hours. Sometimes days.

Excerpt 4 — The Delayed Crash

I went for a walk and felt okay.

Not great. Just okay.

I talked. I moved. I thought I'd managed it. That's the trap.

Twenty minutes later, the fog rolled in thick and heavy. Thinking became like wading through water. I couldn't work out what had changed, only that everything suddenly felt wrong.

This is the part people don't see.

The delay.

Effort doesn't always fail immediately. Sometimes it waits.

Excerpt 5 — Being Misunderstood

People told me I seemed fine. They said it kindly. That almost made it worse.

When symptoms don't behave consistently, you start questioning yourself. When others can't see the problem, you wonder if you're imagining it.

I wasn't asking to be believed about everything.

Just this one thing:

That what I was experiencing was real, even when it didn't make sense.

Excerpt 6 — The Emotional Cost

The hardest part isn't losing ability.

It's losing reliability.

I never know which version of myself will turn up. Some days I feel almost normal. Other days I feel hollowed out, slowed down, disconnected from my own thinking.

Hope rises easily on good days.

It falls just as easily when the fog returns.

Living like this means constantly recalibrating expectations — mine and everyone else's.

Excerpt 7 — The Shared Weight

I see the worry before it's spoken.

I know my condition doesn't belong only to me. Someone else is watching, adapting, carrying concern quietly. That knowledge brings its own kind of pain.

There's guilt in being cared for.

There's fear in knowing someone else is bracing for what might come next.

This illness doesn't travel alone.

Excerpt 8 — Uncertainty

I don't know where this leads.

I know I am still here. I know I can still think, still feel, still care. I also know that none of those things are guaranteed tomorrow.

The fog doesn't lift completely. It shifts. It thickens. It thins.

For now, I live inside it — not cured, not defeated — just navigating what I can see in front of me.

Excerpt 9 — Hallucination

I went for a short walk and noticed a child's bike left on the footpath.

I walked around it, thinking it was an odd thing to see — a bike simply abandoned in the middle of the path. A few steps later I turned back to look again. The bike was no longer there. All that

What my brain showed me

What I saw when I looked back

remained was the painted bicycle symbol on the footpath, marking the shared path.

For a moment, my brain tried to reconcile what I had seen with what was now in front of me. I moved on, aware that small moments like this are becoming part of how I experience the world — ordinary, subtle, and quietly confusing.

Excerpt 10 — Transient Visual Fragmentation On Waking

Fragmented, non-formed visual patterns briefly experienced on waking.

At 7:15 am I wake drenched in sweat, my clothes and skin wet as if I have been running. I close my eyes.

Instead of darkness, I see fractured, shifting patterns — like broken kaleidoscopes, constantly rearranging themselves. There is no single image, no focal point, just motion.

It feels like dreaming while awake, except without a scene or a story. It feels as if my thalamus has gone tripping — misfiring, unable to settle.

After a couple of minutes, the images fade. When I close my eyes again, I can finally see proper blackness. The system resets, and the noise quietens.

Excerpt 11 — A Low Dopamine Day

I wake up but don't fully arrive.

My eyes open, but my body feels confused, slow to respond. The controls are there, but they lag. I'm caught between states — not properly asleep, not properly awake.

When I close my eyes, broken images flash. They don't form dreams. They don't fade into darkness either. It feels like the brain is searching for the wrong signal and returning fragments instead.

Energy is almost absent. Getting up feels theoretical rather than possible. Time stretches. I drift in and out of awareness without resting.

Eventually, I sit up. Everything feels heavy. My head feels dense, like it's not getting what it needs.

On paper, my vital signs would look "fine." That's the problem. What looks acceptable from the outside doesn't match what's happening inside.

Thinking comes in pieces. Long pauses. Words arrive late or not at all.

I want to lie back down. Sleep would be easier. Instead, I push myself forward, not out of strength, but habit. I tell myself to get up. To eat something. To stay connected to the day, even loosely.

Some days, that effort is the only achievement.

Excerpt 12 — Micro-Seizure With Loss Of Recent Memory

When I get very tired, I start passing out in short bursts, which I call micro-seizures. It feels like my brain crashes the way an old computer does — anything I was doing at the time does not get saved.

For example, I might be writing, using my iPad,` a sentence and suddenly stop mid-word. When my brain reboots, I have no memory of what I was writing, only the awareness that something has just failed. I know a seizure has occurred, but the recent events leading up to it are gone.

This can happen repeatedly within seconds. I may start writing again, crash again, and lose the thread each time. Eventually, after several resets, my brain shuts down fully and I fall into deep sleep.

When I wake later, the partial sentences remain, but the context that created them has vanished.

Excerpt 13 — Uncontrollable Muscle Spasms

Sometimes my body moves before I've decided to do anything.

An arm jerks. A leg tightens. My shoulder pulls suddenly, as if someone has tugged a string and let go. It's not painful, but it's not voluntary either. The movement happens first. Understanding comes later.

I'm awake when this happens. I know where I am. I'm not panicking. I'm not anxious. There's no emotional build-up that explains it. The signal just fires, and the body obeys.

It can happen when I'm overtired, when the day has been too full, or when I've tried to push past a limit I didn't realise I'd already reached. Sometimes it happens on its own, without warning. Sometimes it comes in small clusters, like the system is trying and failing to settle.

From the outside, I imagine it looks worrying. From the inside, it feels mechanical — like a crossed wire, or a command sent down the wrong channel.

What's hardest is not the movement itself, but how easily it could be misunderstood. It's not something I can stop by concentrating harder. Telling my body to relax doesn't undo a signal that's already been sent.

Usually, the best response is to stop. Sit or lie down. Let things quieten. When I do that, the movements fade. When I don't, they often get worse.

It's another reminder that this illness isn't just about memory or thinking. Sometimes the brain misfires, and the body answers before anyone can intervene.

Excerpt 14 — The Cards Changed

I'm playing Solitaire on my iPad, carefully checking every possible move. I reach the point where there are no moves left. I click the "Hint" button and it agrees — there is nothing available.

Then something strange happens.

As I continue playing, I find I am about to win, and whoosh — the cards suddenly change into a completely different game. I'm staring at a new layout that I don't remember starting, and this time I can't see a single move.

This happens again. And again.

Over twenty-plus games, the cards “magically” reset themselves three times. There is no animation, no transition, no sense of time passing — just an instant replacement.

I have no memory of touching the screen or starting a new game. My only explanation is that this may be some kind of micro seizure — a brief reset where my brain seems to reboot without saving the last few moments.

Solitaire, which I use as a simple brain exercise, has become a quiet way of watching my mind glitch in real time.

Core Rule (Print This)

Stopping is care.

Calm is medicine.

Pushing causes harm.

I was about to win! Ace of ♠ is under 4 ♠ ...

Whoosh ... the cards change to this ? and I can not win

Appendix B — Medical Safety & Red Flags

(For carers, clinicians, and emergency situations)

⚠️ HIGH RISK CONDITION — LEWY BODY DEMENTIA

People with Lewy Body Dementia can be extremely sensitive to medications, anaesthesia, and physiological stress.

Some routine treatments may cause severe or lasting harm.

This appendix supports clinical awareness and safety. It does not replace clinical judgment or standard medical assessment.

Evidence note

The safety guidance in this appendix is supported by the Medical and Scientific References section at the back of the book.

Purpose

This appendix exists to reduce preventable harm.

It is designed to be shared with medical staff if needed.

People with LBD can appear medically stable and still be at high risk of sudden deterioration after:

- sedation
- surgery
- medication changes
- infections
- dehydration
- hospitalisation

This appendix summarises known high-risk situations and warning signs.

Red Flag 1 — Anaesthesia & Sedation

High risk situations:

- general anaesthesia
- heavy sedation
- procedures described as “routine”

Possible outcomes:

- prolonged delirium
- severe confusion
- hallucinations or psychosis
- rigidity or immobility
- permanent loss of function
- failure to return to baseline

Key rule

Always disclose Lewy Body Dementia before any procedure.

What carers should do:

- ask if the procedure is truly necessary
- ask about alternatives to general anaesthesia
- request minimal sedation
- involve specialists familiar with LBD
- monitor closely after discharge

What not to assume:

- “Routine” does not mean safe
- “Short procedure” does not mean low risk

See Care Protocol 12, p. 84 — Anaesthesia, Surgery & Procedures

Supported by

McKeith et al. (2017); O’Brien & McKeith (2015); LBDA (2020); Mayo Clinic (2025).

Red Flag 2 — Medication Sensitivity

People with LBD often react severely to medications that are commonly used in other conditions.

High-risk medication categories:

- antipsychotics (typical and atypical)
- benzodiazepines
- sedatives
- anticholinergic drugs
- some anti-nausea medications

Common dangerous reactions:

- sudden confusion
- extreme sedation
- rigidity
- collapse
- rapid cognitive decline

What carers should do:

- report any sudden change after medication adjustments
- insist clinicians are aware of LBD diagnosis
- request slow, cautious medication changes

Key reminder

"Start low and go slow" is essential

in Lewy Body Dementia.

See Care Protocol 9, p. 80 — Medication Changes & Sensitivity

Supported by

McKeith et al. (1999, 2007); Schneider et al. (2005); DART-AD (2009); Ballard (2002); Gauthier et al. (2018).

Red Flag 3 — Delirium Vs Lewy Body Dementia

Hospital delirium is common in people with LBD and is often misinterpreted as disease progression.

Delirium may be triggered by:

- infection
- dehydration
- surgery
- medication changes
- unfamiliar environments

Delirium often looks like:

- sudden confusion
- agitation or withdrawal
- hallucinations
- rapid changes over hours or days

Important distinction:

- Delirium can be reversible
- It requires urgent investigation
- Do not assume decline is permanent without assessment

Prolonged low responsiveness or difficulty waking may represent a low-arousal Lewy Body Dementia state rather than acute delirium, particularly in the absence of infection, new medication, or metabolic disturbance.

See Care Protocol 13, p. 85 — Waking from a Low Dopamine / Low Arousal State.

Red Flag 4 — Autonomic Instability

Autonomic dysfunction is a core feature of Lewy Body Dementia.

Watch for:

- sudden blood pressure drops
- fainting
- irregular breathing
- temperature dysregulation
- severe constipation or gut shutdown
- involuntary muscle jerks or spasms (especially if new, worsening, medication-related, or contributing to falls)

What carers should do:

- take symptoms seriously even if tests are “normal”
- ensure hydration
- avoid rapid position changes
- report pattern changes promptly

See Care Protocol 8, p. 78 — Autonomic Episodes

Red Flag 5 — Infection & Dehydration

Even mild infections can cause severe cognitive and functional decline in people with LBD.

Common triggers:

- urinary tract infections
- chest infections
- dehydration

Signs may include:

- sudden confusion
- increased hallucinations
- extreme fatigue
- worsening balance

Important notes:

- Symptoms may appear before fever or pain
- Trust sudden changes in behaviour or cognition

What carers should do:

- Treat sudden cognitive or functional change as urgent, even without fever, pain, or obvious illness
- Encourage fluids immediately (small, frequent sips if needed)

Continued on next page...

- Check for common sources: urine changes, cough, shortness of breath, reduced intake, dark urine
- Seek medical review early — do not “wait and see”
- Tell clinicians this is Lewy Body Dementia and that infections often present *without* typical warning signs
- Document the change: time of onset, behaviour changes, hallucinations, mobility decline
- Avoid assuming psychiatric relapse — infection and dehydration must be ruled out first

When To Seek Urgent Medical Help

Seek urgent help if there is:

- chest pain
- collapse or fainting
- breathing difficulty
- sudden weakness
- rapidly worsening confusion
- inability to rouse
- Difficulty waking or prolonged low responsiveness — especially if worsening or accompanied by breathing changes (*see Care Protocol 13, p. 85 — Waking from a Low Dopamine / Low Arousal State*)

Trust your instincts.

Pattern changes matter more than single measurements.

Core Safety Statement

Lewy Body Dementia changes how the body responds to stress and medication.

Caution saves function.

Advocacy saves lives.

Glossary Of Common Terms

(Lewy Body Dementia — lived experience & care)

Adrenaline "Good Day"

A temporary period of improved clarity or energy caused by stress hormones rather than recovery. These days often lead to overexertion and are usually followed by a significant crash.

See: False Recovery & Adrenaline Days (Core Chapters)

Anaesthesia Sensitivity

An increased risk of severe confusion, delirium, hallucinations, or long-term decline after sedation or general anaesthesia. People with Lewy Body Dementia are particularly vulnerable.

See: Medical Risk & Hospital Harm, Appendix B – Red Flag 1

Autonomic Dysfunction

Failure of the body's automatic control systems. Can affect blood pressure, heart rate, temperature regulation, digestion, breathing, and sweating. Common in Lewy Body Dementia.

See: Appendix B– Red Flag 4

Brain Crash

A sudden neurological shutdown where thinking, speech, and physical capacity collapse without warning. Not tiredness. Not emotional. Requires immediate rest.

See: Brain Crashes Explained, Care Protocol 1

Cognitive Load

The total amount of mental effort being used at any one time. In Lewy Body Dementia, even small increases in cognitive load can trigger overload or a crash.

See: Foggy Brain Day (Protocol 2), Sensory Overload / Shutdown (Protocol 3), and Visual & Cognitive Load Aids (Protocol 11)

Delirium

A sudden, often reversible state of confusion caused by illness, infection, medication, dehydration, or hospitalisation. Frequently mistaken for dementia progression in people with Lewy Body Dementia.

See: Delirium vs Disease Progression, Appendix B – Red Flag 3

Executive Function

The brain's ability to plan, organise, sequence, initiate, and complete tasks. Often impaired early in Lewy Body Dementia.

See: When Thinking Stops Working Properly

False Recovery

A misleading improvement where symptoms temporarily ease, giving the impression of recovery. Often driven by adrenaline and usually followed by deterioration.

See: False Recovery & Adrenaline Days, Care Protocol 6

Fog / Foggy Brain

A state of mental clouding where thinking is slow, unclear, and unreliable. The person may appear present but cannot process information normally.

See: Living in the Fog (Core Chapters)

Fluctuations

Rapid and unpredictable changes in cognition, alertness, or physical ability. A defining feature of Lewy Body Dementia.

See: Why Yesterday Doesn't Predict Today

Hallucinations

Seeing, hearing, or sensing things that are not present. In Lewy Body Dementia, these are often visual and can occur early in the illness.

See: Hallucinations & Misinterpretation

Involuntary Muscle Spasms / Jerks

Sudden, uncontrollable muscle movements such as jerks, spasms, or brief tightening that occur without intention. In Lewy Body Dementia, these movements are often neurological misfires rather than anxiety, behaviour, or epileptic seizures, and may fluctuate with fatigue, stress, illness, or medication sensitivity.

See: Involuntary Muscle Spasms & Jerks (Plain English), Autonomic Failure

Lewy Body Dementia (LBD)

A neurodegenerative condition caused by abnormal protein deposits (Lewy bodies) in the brain. Characterised by cognitive fluctuations, visual hallucinations, Parkinsonian symptoms, sleep disturbance, and autonomic dysfunction.

See: What Lewy Body Dementia Is (and Isn't)

Medication Sensitivity

An exaggerated or dangerous reaction to medications that are otherwise commonly used. Particularly relevant to antipsychotics, sedatives, and anticholinergic drugs in Lewy Body Dementia.

See: Medication Risk, Care Protocol 9, Appendix B – Red Flag 2

Micro-Seizure (Experiential / Non-Convulsive)

A brief episode in which the brain temporarily shuts down and restarts, causing loss of recent, unsaved information. During a micro-seizure, the person may appear awake but experiences an abrupt interruption of thought, speech, or action. When awareness returns seconds later, the individual often knows a failure occurred but cannot recall what was happening immediately beforehand.

In this book, micro-seizures are described as a "brain reboot without saving," similar to a computer crash. These events differ from ordinary forgetfulness or fatigue and may occur repeatedly before the brain forces deep sleep to recover.

See: Micro-Seizures and Memory Loss in Real Time — Appendix A, Brain Crash, Thalamic Filtering Failure

Neuroleptic Sensitivity

A severe and potentially life-threatening reaction to antipsychotic medications, including rigidity, confusion, immobility, and collapse. Common in Lewy Body Dementia.

See: Medication Risk, Appendix B – Red Flag 2

Neuroplasticity

The brain's limited ability to adapt by using alternative pathways or networks to compensate for damage.

See: Neuroplasticity & Adaptation (Plain English)

Overload

A state where sensory, cognitive, or emotional input exceeds the brain's ability to cope, leading to distress, withdrawal, anger, or shutdown.

See: Sensory Overload, Care Protocol 3

Parkinsonism

Movement symptoms such as stiffness, slowness, tremor, or balance problems. Common in Lewy Body Dementia.

See: Movement Changes in LBD

REM Sleep Behaviour Disorder (RBD)

A sleep disorder where people physically act out dreams. Often precedes other symptoms of Lewy Body Dementia by years.

See: Sleep, Dreams, and Night-Time Risk

Sensory Sensitivity

Heightened sensitivity to noise, light, movement, or visual clutter. Can trigger overload or brain crashes.

See: Sensory Overload, Care Protocol 3

Shutdown

A protective response where the brain reduces function to prevent further harm. Appears as withdrawal, silence, or immobility.

See: Brain Crashes Explained, Care Protocols 1 and 7

Start Low, Go Slow

A medication principle meaning doses should begin very small and increase cautiously. Essential in Lewy Body Dementia.

See: Medication Risk, Appendix B – Red Flag 2

Threshold

The point at which accumulated stress, effort, or stimulation triggers a crash or overload. Thresholds are lower and unpredictable in Lewy Body Dementia.

See: Why Pushing Makes Things Worse

Visual & Cognitive Load Aids

Practical tools used to reduce input to the brain, such as narrowing visual fields, reducing light, or simplifying environments (e.g. bucket hat, anti-fatigue glasses).

See: Practical Adaptations, Care Protocol 11

Withdrawal

Pulling back from interaction or activity as a protective response to overload. Not rudeness. Not depression. Not refusal.

See: Misread Behaviours, Care Protocols 3 and 7

Appendix — Medical And Scientific References (Trusted Sources)

This book is written from lived experience and supported by established medical and scientific research. The references below were selected because they directly support the practical strategies in the ‘Care Protocols’ section, and the safety and clinical guidance in Appendix B.

A) Core Facts & Diagnosis

1. Kosaka, K. (2014). Lewy body disease and dementia with Lewy bodies. Proceedings of the Japan Academy, Series B, 90(8), 301–306. https://doi.org/10.2183/pjab.90.301
2. McKeith, I. G., et al. (2017). Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium. Neurology, 89(1), 88–100.
3. McKeith, I. G., et al. (2005). Dementia with Lewy bodies. The Lancet Neurology, 4(12), 673–683.
4. O’Brien, J. T., & McKeith, I. G. (2015). Dementia with Lewy bodies: Diagnosis and management. The British Journal of Psychiatry, 206(2), 156–163.
5. National Institute on Aging (2023). What Is Lewy Body Dementia? (Public education + treatment overview).
6. NHS (2023). Dementia with Lewy bodies (public health overview + symptom patterns).

7. Alzheimer's Association (2023). Dementia with Lewy bodies (DLB) overview.

B) Medication Danger Zone (Appendix B "Red Flags" Backbone)

8. McKeith, I. G., et al. (1999). Sensitivity to neuroleptics in Lewy body dementia: The "litmus test". International Psychogeriatrics, 11(4), 399–408.
9. McKeith, I. G., et al. (2007). Sensitivity to antipsychotics in people with Lewy body dementia. The Lancet Neurology, 6(6), 501–506.
10. Schneider, L. S., Dagerman, K. S., & Insel, P. S. (2005). Risk of death with atypical antipsychotic drug treatment for dementia: Meta-analysis. JAMA, 294(15), 1934–1943.
11. Ballard, C., et al. (2009). DART-AD: Long-term follow-up of antipsychotic withdrawal in dementia. The Lancet Neurology, 8(2), 151–157.
12. Boada, M., et al. (2017). Antipsychotic use and risk of death/cardiovascular events in neurodegenerative disorders. Alzheimer's & Dementia, 13(5), 530–538.
13. Lewy Body Dementia Association (2020). Medications for Behavioral Changes in LBD (clinical guidance PDF).
14. Mayo Clinic (Updated June 21, 2025). Lewy body dementia — diagnosis & treatment (strong public-facing medication cautions).

C) Sleep, Rem Sleep Behavior Disorder, And The “Night Chaos” Pathway

15. American Academy of Sleep Medicine (2023). Clinical practice guideline: Management of REM sleep behavior disorder in adults. Journal of Clinical Sleep Medicine.
16. Boeve, B. F. (2010). REM sleep behavior disorder and implications for diagnosis/treatment of neurodegenerative disease. Current Neurology and Neuroscience Reports, 10(6), 437–446.
17. Ferman, T. J., et al. (2002). REM sleep behavior disorder precedes dementia (prodromal signal). Neurology, 59(1), 107–111.
18. Ferman, T. J., & Boeve, B. F. (2007). Sleep disturbances and cognitive fluctuation in DLB. Nature Clinical Practice Neurology, 3(10), 562–570.

D) Delirium Vs Lbd Fluctuation (Appendix B “Don’t Miss This” Section)

19. Maldonado, J. R. (2008). Pathoetiological model of delirium: Neurobiology, prevention, treatment. Critical Care Clinics, 24(4), 789–856.

E) Falls, Vision, And “Simple Fixes That Prevent Disaster”

20. van der Zwaag, M. D., et al. (2012). Adverse effects of psychotropic drugs in older people: Focus on falls. Drugs & Aging, 29(6), 491–502.

21. Lord, S. R., Dayhew, J., & Howland, A. (2002). Multifocal glasses impair depth/contrast and increase falls risk. Journal of the American Geriatrics Society, 50(11), 1760–1766.

22. Haran, M. J., et al. (2010). VISIBLE RCT: Single-lens distance glasses reduce falls in multifocal wearers. BMJ, 340, c2265.

F) Diabetes + Brain Fog Overlap

23. Biessels, G. J., & Despa, F. (2018). Cognitive decline and dementia in diabetes mellitus: Mechanisms and clinical implications. Nature Reviews Endocrinology, 14(10), 591–604. https://doi.org/10.1038/s41574-018-0048-7

This is a **FREE Preview Edition** of Navigating the Fog: Living with Lewy Body Dementia.

Please support the continued distribution of free copies to people living with Lewy Body Dementia, carers, families, and medical professionals by purchasing an official printed copy of *Navigating the Fog*, or by sharing this book with someone who may find it helpful.

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available formats and ordering options.

Lewy Body Dementia is unpredictable.

It fluctuates, hides, and often looks very different from the outside than it feels from within.

Navigating the Fog was written by someone living with Lewy Body Dementia — not to dramatise it, but to make sense of it. This book describes what cognitive fog, sudden crashes, sensory overload, and delayed recovery can feel like, while also offering practical guidance that improves safety and daily life.

Inside, you will find:

- clear explanations of common but misunderstood symptoms
- practical care protocols designed for real-world use
- guidance for carers navigating uncertainty and risk
- medical safety information to support better care decisions
- optional lived-experience excerpts for recognition, not obligation

This is not a medical textbook.

It is not a diary.

And it does not promise easy answers.

It is a companion for people living with Lewy Body Dementia, and for those caring for them — written to reduce confusion, increase safety, and remind you that what you are experiencing is real.

A practical guide grounded in lived experience and supported by established medical research

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